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The cost of cancer registry operations: Impact of volume on cost per case for core and enhanced registry activities

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Abstract

Background—Cancer registration data is vital for creating evidence-based policies and interventions. Quantifying the resources needed for cancer registration activities and identifying potential efficiencies are critically important to ensure sustainability of cancer registry operations.

Methods—Using a previously validated web-based cost assessment tool, we collected activity-based cost data and report findings using 3 years of data from 40 National Program of Cancer Registry grantees. We stratified registries by volume: low-volume included fewer than 10,000 cases, medium-volume included 10,000–50,000 cases, and high-volume included >50,000 cases.

Results—Low-volume cancer registries incurred an average of \$93.11 to report a case (without in-kind contributions) compared with \$27.70 incurred by high-volume registries. Across all registries, the highest cost per case was incurred for data collection and abstraction (\$8.33), management (\$6.86), and administration (\$4.99). Low- and medium-volume registries have higher costs than high-volume registries for all key activities.

Conclusions—Some cost differences by volume can be explained by the large fixed costs required for administering and performing registration activities, but other reasons may include the quality of the data initially submitted to the registries from reporting sources such as hospitals and pathology laboratories. Automation or efficiency improvements in data collection can potentially reduce overall costs.

Keywords

Cost; Cancer registry; Economics

1. Background

Annually, more than 1.4 million people in the United States are diagnosed with cancer, and these cancer cases are recorded by cancer registries (U.S. Cancer Statistics Working Group, 2013). Cancer registries play a critical role in providing the information needed to develop comprehensive and targeted cancer control interventions to reduce the burden of cancer.

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Information about cancer incidence is needed to evaluate cancer trends; identify and address cancer disparities; and track progress toward cancer prevention and control goals, such as those established by Healthy People 2020 (U.S. Department of Health and Human Services, 2014).

In 1992, the U.S. Congress passed the Cancer Registries Amendment Act, which authorized the Centers for Disease Control and Prevention (CDC) to establish the National Program of Cancer Registries (NPCR) and provide financial support and technical assistance to state health departments for the operation of central population-based cancer registries to collect complete, timely, and high quality data on cancer incidence. Currently, the NPCR supports cancer registries in 45 states, the District of Columbia, Puerto Rico, and the Pacific Island jurisdictions (Centers for Disease Control and Prevention, 2015). The NPCR and the Surveillance, Epidemiology and End Results (SEER) Program provide support to cancer registries in all 50 states, covering the entire United States population (National Cancer Institute, 2015). In addition to the federal initiatives, states also provide significant matching funds to support the operations of cancer registries.

Although some prior studies have reported on the cost of cancer registry operations, there has been no systematic assessment of the cost expended on specific activities performed by the registries. A previous study estimated the average cost per case reported by NPCR-funded registries and identified factors that explained state variations (Weir, Berg, Mansley, & Belloni, 2005). However, that study underestimated the true cost (with a median cost per case of \$18.43 and range from \$3 to \$230), as state funding and in-kind contributions were not included. Other studies have reported activity-based costs collected from a small number of cancer registries (median cost per case of \$45.84 ranging from \$30 to \$100) though their findings cannot be generalized to the overall U.S. population (Tangka, Subramanian, Cole Beebe, Trebino, & Michaud, 2010; Subramanian, Tangka, Green, Weir, & Michaud, 2009). Identifying the resources required for cancer registration activities and increasing efficiencies is critically important to ensure optimal use of the funding available from federal, state, and in-kind contributions.

The objective of the current study was to estimate the average cost per single cancer case for each key registration activity performed by NPCR-funded registries using more representative data and more complete data than prior studies. Central cancer registries perform a large number of core surveillance (key activities related to collection of cancer incidence data and maintenance of the registry database [Appendix Table A1]), data enhancement, and analysis activities. Previous analyses have observed potential economies of scale in registration operations or noted that further research is needed to understand variations in cost per case across registries (Weir et al., 2005; Tangka et al., 2010). In this study, we stratify registries based on volume to explore the cost per case incurred in each group for specific registration activities. Our findings may help to quantify the resources needed for cancer registration activities, lead to understanding of variations in cost per case for specific activities, and identify approaches that can improve the efficiency of registry operations.

2. Methods

We used a previously developed web-based Cost Assessment Tool (web-CAT) to collect activity-based cost data from the 48 NPCR-funded registries. The NPCR web-CAT was developed using economic evaluation theory and activity-based costing methodology (Anderson, Bowland, Cartwright, & Bassin, 1998; Drummond, Sculpher, Torrance, O'Brien, & Stoddart, 2005; French, Dunlap, Zarkin, McGeary, & McLellan, 1997; Salome, French, Miller, & McLellan, 2003). Details on the web-CAT development and validation have been previously reported (Subramanian et al., 2007; Subramanian, Ekwueme, Gardner, Bapat, & Kramer, 2008). The web-CAT allows for data collection across budget categories, including labor, consultant and contract expenditures, computer software and hardware, travel and training, and administrative or overhead expenses. The NPCR web-CAT includes 10 screens that collect data on various aspects of registry operations: (1) descriptive details on the registry itself, including program type; (2) total expenditures (all funding sources); (3) inkind contributions; (4) personnel expenditures; (5) personnel activities; (6) consultant/ contractor expenditures; (7) computers, travel, training and other expenditures; (8) software expenditures and details on the database management software used by the registry; (9) administrative costs; and (10) factors affecting registry operations (including number of cases reported, records received, data submission formats). In addition, a final screen provided a summary of the data reported by the registry and a confirmation screen allowed the user to submit the data. In addition to introductory information with background on the economic evaluation of the NPCR and general instructions on entering, saving, and submitting data, the user's guide also provided detailed information and instruction for each web-CAT screen.

Registry staff members (often the registry director) were asked to allocate expenditures (including employee time) to various program activities. The cost data was reported retrospectively and registry staff allocated actual expenditure to specific activities. To ensure that data was standardized across the registries, we offered training webinars, a detailed user's guide with definitions for each activity, and ongoing technical assistance to address any questions about data collection and reporting. The percent time reported was provided by the registry staff and then multiplied by the annual salary (or actually time spent if it is less than 12 months). The cost for each activity was summed up.

Cost data were collected for a 3-year period (program years 2008–2009, 2009–2010, 2010–2011) on registry funding (including in-kind contributions), expenditures, number of cases reported, and factors that might affect the efficiency of operating a central cancer registry. We collected cost data for multiple years to account for variations in registry activities and costs from year to year. In addition, because cases are collected and processed on a continual basis (takes up to two years to collect complete data on a case), we used the number of cases reported during the cost data collection period to calculate the cost per case. This is based on methodology previously used and since cases do not vary dramatically between years, the number reported provide a good approximation of the cases at various stages of completion in any given funding period (Subramanian et al., 2009). Given the two year delay in reporting cancer cases, we used cancer cases diagnosed in 2006, 2007 and 2008 for the program years 2008–2009, 2009–2010, 2010–2011 respectively. In addition, to standardize

calculations for cost per case, we limited the cases used in the analysis to in-state cases collected by the registry.

We used a programmatic perspective, taking into account all resources, regardless of funding source, in our activity-based cost assessment. In-kind contributions included nonmonetary assistance and support provided to the registries. In-kind labor contributions include physician consultation to the registry, IT services, and time spent by state administrator to support registry activities while in-kind non-labor contributions include supplies and materials, and office space. Registries reported in-kind contributions directly and also provided the method used for estimating the value of each contribution. Reported methods include internal best estimates, market value, and foundation budget amounts (when resources were allocated to provide goods/services to the cancer registry).

We performed a series of data checks to ensure the accuracy of the data reported by registries. Several of these data checks were automated within the web-CAT (for example, totals of each allocation category sum to 100% and funds expended match expenditure allocated for the fiscal year), which ensured that final submission met key data quality standards. We limited the difference between reported funding and total expenditures allocated to specific activities to within a difference of 5%. We also required reported time spent on activities to total 100% for each registry employee. In cases where a registry used a major contractor, both the registry and the contractor were required to submit data via the web-CAT. To facilitate the aggregation of registry and contractor data and to avoid double counting, reported funding for both the contractor and registry were linked.

Finally, we further validated the data by comparing reported NPCR funding in the web-CAT with funding amounts in CDC records. Each registry-reported number of cancer cases was compared with CDC internal records and United States Cancer Statistics (USCS) cancer cases; these served as guidelines for assessing accuracy, as cases were not expected to match exactly (registries may report additional cases not required by CDC or USCS). Registries reviewed and approved summaries of the validated data following each of the three rounds of data collection.

To create activity-based cost data files, we first allocated costs to specific registry activities by totaling the cost of each registry activity across all budget categories. For example, in terms of personnel costs, the percent time reported by the registry staff was multiplied by the annual salary (or actually time spent if it is less than 12 months) and then the cost for each activity was summed up. Next, we added together expenditures that did not have any associated registry activity and prorated those across all registry activities. We adjusted cost per case for regional cost of living using the Employment Cost Index (U.S. Bureau of Labor Statistics, 2014).

Overall, seven NPCR-funded registries also receive cases collected through the SEER Program. To avoid misinterpreting any unmeasured differences between these registries and the other NPCR registries, we excluded these observations from the analysis. In addition, we also excluded the Pacific Regional Central Cancer Registry as this registry was not yet fully operational during the data collection period.

We stratified the 40 remaining registries by volume based on natural breaks and outliers present in the data; low-volume included those with fewer than 10,000 cases, medium-volume were those with 10,000–50,000 cases, and high-volume were those with more than 50,000 cases. The mean number of cases reported among low-volume registries was 5738 (with a standard deviation of 2433). Medium-volume registries had a mean of 26,232 (10,343) cases reported. High-volume registries had a mean of 92,642 (19,415) cases reported.

We noted the key characteristics of the registries including program type (health department, contractor, or private organization), geographic region, size of area served (using U.S. Census data, we classified geographic areas as small [less than 42,000 square miles], medium [42,000–69,000 square miles], or large [more than 69,000 square miles]), software used, and consolidation effort (number of cases reported versus number of records received). We also examined the certification status of each registry with the North American Association of Central Cancer Registrars (NAACCR) to assess the quality of the data submitted. NAACCR certifies registries annually for the most recent year of incidence data reported, to identify registries that have complete and accurate data for computing cancer incidence statistics (NAACCR, 2015). Finally, we logged the portion of cases from reporting sources that passed automatic edits (indicating high quality data) and whether a significant portion of the records were received via electronic submissions.

Using volume stratification, we present a detailed assessment of funding, in-kind contributions, and cost per case, both overall and by registry activity. The average cost and the 95% confidence interval are reported as appropriate. We ran multivariate tests of means (Wilks' lambda, Pillai's trace, Lawley-Hotelling trace, Roy's largest root) to compare the registry characteristics and the means of the cost per case variables for each of the three volume categories: low, medium, and high. Means that were significantly different (10% or better) across the groups are identified in the table and text.

3. Results

Table 1 presents the registry characteristics overall and stratified by volume categories. The majority of the registries were part of health departments, and few used contractors or were run by private organizations. Of the 40 registries included in our analyses, 17.5% were located in the Northeast, 37.5% were located in the South, 25.0% were in the Midwest, and 20.0% were in the West. While medium-volume registries were fairly evenly distributed among small, medium, and large areas served, low-volume registries served very few (7.7%) medium-sized areas (F = 6.77). High-volume registries tend to use internally developed tools at a significantly higher rate than low- or medium-volume registries (F = 3.80). The consolidation effort varied across registries but this difference was not statistically significant. Medium and larger registries were more likely to have achieved NAACCR gold standards (more than 80% compared with about 70%) and there were a significantly larger proportion of low volume registries who achieved silver status. High-volume registries had significantly larger proportions of records that were reported electronically (F = 2.95) and also had significantly higher percentages of records that passed 100% of the edits at the time of data submission (F = 2.73).

Table 2 reports the funding amount and sources of the funding. The average amounts (standard deviations in parentheses) of annual funding for low-, medium-, and high-volume registries were \$482,198 (\$138,706), \$1,051,410 (\$417,145) and \$2,858,425 (\$1,695,795), respectively. Multivariate tests of means indicate these estimates were significantly different across the volume categories (F = 24.04). On average, the NPCR was the largest source of funding for the low- and medium-volume registries (F = 26.25) while on average nonfederal sources (generally states) provided the most funding for high-volume registries (F = 14.90). Total in-kind contributions increased with the size of registries from an average of \$163,793 (\$132.219) among low-volume registries to \$828,380 (\$1295,043) and \$1014,821 (\$1967,004) among medium- and high-volume registries respectively, though the differences in means across volume categories was not statistically significant.

Table 3 presents the cost per case of core and enhanced activities for each reporting period and averaged across the 3 years. Most of the registry funds, more than 90%, were spent on core registry activities (such as registry management, case ascertainment, and quality assurance activities) while only a small portion of funds, about 7%, was allocated to enhanced registry activities (such as implementing cancer inquiry response systems, performing research studies, and publishing research study results). The average cost per case for core registry activities (F = 12.26) was \$93.11, \$42.10, and \$27.70 for low-, medium-, and high-volume registries, respectively, while the distribution of enhanced activities (F = 8.02) was \$7.77, \$2.76, and \$1.82, respectively. Similarly, with the inclusion of in-kind contributions, the average cost per case for core registry activities (F = 6.04) was \$124.82, \$70.09, and \$36.03 for low-, medium-, and high-volume registries, respectively, while the distribution of enhanced activities (F = 5.06) was \$9.75, \$4.90, and \$2.42, respectively.

Fig. 1 presents the cost per case for the 12 cancer registry activities with the highest costs, while Table 4 presents the average annual cost per case and differences across the registries by volume for the same activities. Overall, across all the 40 registries, the highest cost per case was incurred for data collection and abstraction (\$8.33), management (\$6.86), and administration (\$4.99). Other activities – including analyzing and reporting, visual editing (viewing and correcting data manually), and database management – ranged from \$2.40 to \$3.40 per case reported. Across all the key activities, the cost per case for the high-volume registries was the lowest, followed by the medium-volume registries. The magnitude of the cost difference was largest for the top three activities based on cost per case: data collection and abstraction, management, and administration. For these activities, the difference between low- and high-volume registries ranged from \$7.02 to \$10.01 and, similarly, for medium- versus high-volume registries, the range was from \$3.21 to \$6.19. For all the top-12 activities, except IT support, the difference between low-volume and high-volume registries was much larger than that between medium- and high-volume registries.

4. Discussion

We reported on the differences in the cost incurred by NPCR-funded central cancer registries based on the volume of cancer registrations carried out by the registries. Based on analyses of 3 years of cost data from 40 registries, we identified large variations in the

average cost per case for core registration activities. Low-volume cancer registries incurred \$93.11 on average (without in-kind contributions) to report a case compared with an average of \$27.70 incurred by high-volume registries. In-kind contributions were received by all registries, with high-volume registries reporting the largest amounts and proportions compared to total funding. Despite these contributions, high-volume registries still had the lowest cost per case. Across all registries, more than 90% of the cost was allocated to core activities, and these patterns remained the same by volume across registries for core and enhanced activities, with high-volume registries incurring the lowest cost per case. Our results support previous studies that have reported significant economies of scale in cancer registries and programs (Weir et al., 2005; Tangka et al., 2010).

Across all registries, as expected, the highest cost was incurred for performing data collection and abstraction, with an average cost per case of \$8.33. The next highest cost categories were management and administration, with cost per case of \$6.86 and \$4.99, respectively. All other activities had costs under \$3.50 per case. Average cost estimates derived across all registries do not provide an accurate picture of the true cost of registration activities, as there are systematic differences due to the consistent relationship between cost per case and volume for all major activities performed by cancer registries. High-volume registries experience lower cost per case for data collection and abstraction, case ascertainment, visual editing, database management, and training of staff. Overall, low-volume registries had consistently higher cost per case for all activities compared to medium-volume registries.

There are several differences in the characteristics of the registries by volume which can explain the large differences in cost reported for data collection and abstraction. Medium-and high-volume registries have a higher proportion of records submitted electronically, and high-volume registries also have larger proportions of cases passing 100% edits at the time of data submission (indicating that the initial submission to the registries is of high quality).

Overall, these differences indicate that high- and medium-volume registries are likely to receive better quality data than are low-volume registries, explaining to some extent the need for additional resources (\$10.01 more for low- and \$6.19 more for medium-volume registries, compared with high-volume registries) to review, re-abstract, and improve completeness and accuracy of the data. If the process of compiling a case is automated, as in medium- and high-volume registries, then any differences in the number of records may only have a negligible influence on resources required. One potential approach would be to examine whether efficiencies could be achieved in low-volume registry operations by increasing electronic submissions and implementing automated quality review processes.

Program management and administration activities also had substantial variation in cost per case, possibly because of the significant fixed costs associated with these activities. That is, regardless of the size of a registry, there are management and administrative activities that must take place to facilitate the cancer registration process. Collaborative registration activities or sharing resources among state programs, particularly for low-volume programs in nearby states, might help reduce some of these fixed costs. Lessons can be learned from

regional cancer registries that cover wide areas but collaborate to produce state-specific statistics.

Overall, there was a consistent pattern in the differences in the cost per case across all key registry activities. This indicates that there could be fixed costs associated with many of the registration processes. Additional research is required to accurately assess the proportion of fixed versus variable components of these activities. In this study, we used a top-down costing approach to assign activity-based costs; however, a bottom-up costing approach could be used in the future to identify the fixed, variable, and semi-variable nature of labor and non-labor resources required for key registration activities.

Adequate resources and efficient use of available funding are essential to ensuring high quality cancer registration data. There is some variation in the quality of the data reported by cancer registries, with high- and medium-volume registries more likely to receive NAACCR gold certification than low-volume registries (data presented in Table 1). Low-volume registries may fail to meet the highest levels of certification because of several reasons, including the quality of the data that is initially submitted to the registries, inefficiencies in the processes employed, and lack of resources needed to achieve high quality given the large fixed costs of cancer registration activities.

A potential limitation of the data analysis presented in this study is that the registries report data retrospectively, and the potential for error makes the reliability of retrospective data uncertain. However, registries were provided with detailed user's guides and technical assistance to ensure that the highest quality data was compiled for this study. All sites made use of the user's guide and attended training webinars; some sites were more intensive users of one-on-one technical support than others. A second limitation might be the geographic diversity of the registries. Even though the cost data were adjusted to control for regional variations in costs, we may not have been able to fully account for differences. Third, registration activities for a single cancer case can occur over several years. Although we used 3 years of data, there might have been a mismatch between registry cost and the reporting of cancer cases. Fourth, we only had a small number of registries in the high volume group compared to the other groups. Fifth, the staffing mix, in terms of seniority and training, can impact cost and data quality and we did not have detailed information to analyze this impact.

5. Lessons learned

The findings presented in this study provide a detailed assessment of the cost per case by volume of cancer registration to assist policy makers and cancer registry directors to improving operational efficiency. Comparing average cost of registry activities may distort the true cost of cancer registration, as low- and high-volume registries have differing cost structures. Some of these differences can be explained by the large fixed costs required for performing registration activities which include the overall data collection infrastructure and the management/administration oversight. Forming multi-state or regional partnerships can lead to lower cost per case as fixed cost of resources could be shared across multiple registries and economies of scale can be realized. Another reason might be the quality of the

data initially submitted to the registries. Automation or efficiency improvements could potentially reduce overall costs; for example, the use of electronic transmissions could significantly lower data collection and quality assessment costs. Additional research is needed to clarify the cost-benefit of implementing or expanding electronic data exchange as this will require some initial investment which will then result in data quality improvements and economic efficiency over time. Furthermore, micro-costing of time spent on specific high cost activities will provide valuable insights into the use of electronic systems and potentially task shifting to lower cost employees to increase cost-effectiveness of registry operations.

Appendix A

Table A1

Activity definitions used in the U.S. National Program of Cancer Registries—cost assessment tool.

Core activity definitions

- 1. Management: Addressing personnel and staffing issues; serving as liaison to other states and organizations; participating in NPCR, NAACCR, and NCRA committees; preparing registry applications and reports
- 2. Administration: Mailing, filing, logging, and other clerical tasks
- 3. Training of registry staff: Training of central registry staff; providing educational opportunities for staff, registry staff attending training-focused workshops such as NPCR Education and Training Coordinators, NAACCR, and NCRA; and leading meetings, webinars, conference calls, and other state and local training opportunities
- **4. Training of others by registry staff:** Training CTRs as part of continuing education and other activities where registry staff trains those not working at the central registry. This includes answering QA questions and material development
- 5. Database management: Managing datasets for registry operations and special studies
- **6. IT support:** Managing and supporting software updates, hardware upgrades, network maintenance, and creation of new systems and interfaces
- 7. Case ascertainment: Processing pathology reports, following up with physicians regarding pathology reports, and reviewing charts or reports
- 8. Death certificate clearance: Identifying incoming data sources, obtaining data from incoming sources, determining record and file structure, matching incoming records with cases in database, following up on cases requiring additional information, and determining statistical codes to update cases
- **9. Data collection/abstraction/data processing:** Collecting, abstracting, and processing registry data from all health care providers
- 10. Analyzing data and generating reports: Performing descriptive and statistic data analysis and generating reports from the results
- 11. Sharing cases: Creating data-sharing agreements; facilitating or negotiating data-sharing agreements; creating, preparing, and submitting cases for data sharing; importing and editing incoming cases from data-sharing sources
- 12. Electronic case reporting and data encryption: Maintaining and increasing electronic case reporting from health care providers, including encrypting data
- 13. Call for data reporting requirements to CDC, NAACCR, and interstate data exchange: Preparing cases for required reporting years, preparing documentation required for reporting, reviewing cases from reporting agencies after data is submitted, and requesting resubmissions when required
- 14. Automatic case-finding and updating use of electronic links: Linking to electronic data sources and finding cases automatically through such linkages
- 15. Geocoding cancer cases: Attaching geographic identifier to the cancer registry data
- **16. QA: Visual editing:** Manually evaluating the accuracy of a submitted case by comparing codes with supporting text or documents to find inconsistencies that may be missed by electronic edits, notifying reporters of errors, receiving corrections, and processing them
- 17. QA: Computer editing: Reviewing computer-generated edit reports for possible overrides or errors, notifying reporters, receiving corrections if needed, and processing final reports

Core activity definitions

18. QA: Consolidating: Combining patient, tumor, and treatment information reported from multiple sources for each patient and tumor into one record that has complete and accurate information for the database

- 19. QA: Tracking dataflow: Monitoring the status of a case from its initial submission through the central registry processes until it is complete and added to the database
- 20. QA: Tracking completeness and timeliness: Determining the percentage of expected cases within a specific time period, calculating the reporting performance including completeness and submittal delay time, and notifying reporters of their status
- 21. QA: Auditing: Re-coding, re-abstracting, or reviewing case-ascertainment studies to assess the accuracy and completeness of facility reporting
- 22. Linking records to other state or national datasets: Creating and submitting data files to reporting agency as specified for matching and linking, incorporating linked records into each state's data management system, procuring additional incoming data sources, importing cases from linked data sources, performing visual reviews, and updating cases from linked sources

Enhanced data and analysis activity definitions

- 23. Implementing a cancer inquiry response system: Answering requests for data and other cancer inquiry response system activities
- 24. Active follow-up: Performing active, rather than passive, follow-up as necessary
- 25. Research studies and other analysis using registry data: Investigating cancer clusters, performing special studies, and conducting other research and analysis using registry data
- **26. Publication of research studies using registry data:** Preparing research studies resulting from registry data for publication

Abbreviations: CTR, Cancer Tumor Registrar; NAACCR, North American Association of Central Cancer Registries; NCRA, National Cancer Registrars Association; NPCR, National Program of Cancer Registries; QA, Quality Assurance.

Biographies

Sujha Subramanian, PhD—Dr. Subramanian is a Fellow in Cancer Economics and Policy at RTI International. She has been working on cost-effectiveness and economic evaluation of cancer programs for more than 15 years. She also currently serves as a Senior Visiting Scientist at the World Health Organization's International Agency for Research on Cancer (WHO-IARC).

Florence K.L. Tangka, PhD—Dr. Tangka is a health economist in the Division of Cancer Prevention and Control at the Centers for Disease Control and Prevention (CDC). Her main areas of research are cost of cancer care, economic evaluation of cancer screening programs and economic assessment of the cost of cancer registration in the United States and the international setting.

Maggie Cole Beebe, PhD—Dr. Cole Beebe is a research economist in RTI International's Health Care Financing and Payment program. She conducts a variety of quantitative analyses including costing studies for cancer programs and payment reform evaluation for Medicare initiatives.

Diana Trebino, MPH—Ms. Trebino was a research scientist at RTI and played a key role in collecting and analyzing data from all National Program of Cancer Registry grantees. She developed processes for data quality assessment and generated state-specific reports to assist policy makers in reaching funding decisions concerning cancer registration activities.

Hannah K. Weir, PhD.—Dr. Weir is a senior epidemiologist in the Division of Cancer Prevention and Control's Epidemiology and Applied Research Branch at the CDC. Herresearch focus is primarily in the area of cancer surveillance, with a particular focus on population-based cancer survival.

Frances Babcock, CTR—Ms. Babcock is the Deputy Branch Chief in the Cancer Surveillance Branch of the Division of Cancer Control and Prevention at the CDC. She oversees registry operations and provides guidance for funding decisions.

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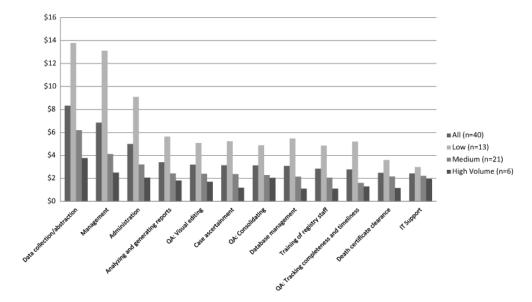


Fig. 1. Average cost per case for top 12 registry activities by volume of cases.

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Table 1

Selected characteristics of the NPCR registries by volume of cases.

tion) 1.	АШ			Low volume		Medium volume		High volume		F statistic
rype 5.738 (2,433) 26,232 (10,343) rype 1 clepartment 2 7.5% 8 61.5% 16 76.2% department with major contractor 8 20.0% 4 30.8% 3 14.3% e or other organization 3 7.5% 1 7.7% 2 9.5% east 1 17.5% 4 30.8% 1 4.8% east 1 17.5% 4 30.8% 1 4.8% east 1 25.0% 3 23.1% 5 22.4% east 1 25.0% 4 30.8% 4 19.0% reast 1 25.0% 4 30.8% 4 19.0% reast 2 1 35.5% 6 46.2% 8 23.8% see 1 35.5% 1 7.7% 7 28.8% see 1 35.5% 1 7.5% 1 25.8% 1 23.3% <th></th> <th>Z</th> <th>9</th> <th>N = 13</th> <th></th> <th>N = 21</th> <th></th> <th>9 = N</th> <th></th> <th></th>		Z	9	N = 13		N = 21		9 = N		
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o department 29 7.2.5% 8 61.5% 16 76.2% o department with major contractor 8 20.0% 4 30.8% 3 14.3% e or other organization 3 7.5% 1 7.7% 2 14.3% east 15 37.5% 4 30.8% 1 4.8% east 16 25.0% 3 23.1% 5 23.4% est 10 25.0% 4 30.8% 4 19.0% est 10 25.0% 4 30.8% 4 19.0% est 20.0% 4 6 46.2% 7 23.8% m 35.5% 1 7.7% 7 23.8% leat 25.0% 3 23.1% 6 28.6% leat 35.5% 1 7.5% 7 28.6% leat 4 5 2 23.1% 1 33.3% leat 5 <td>Program type</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td>	Program type									
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east cardination	Health department with major contractor	∞	20.0%	4	30.8%	3	14.3%	1	16.7%	89.0
east 1 17.5% 4 30.8% 1 4.8% est 1 5.24% est 1 25.0% 3 2.1% 5 23.8% est 1 25.0% 4 30.8% 11 5.24% est 1 25.0% 4 30.8% 4 19.0% era served 14 35.0% 6 46.2% 8 38.1% enable effort 13 32.5% 1 7.7% 7 33.3% era properties of the served 13 32.5% 1 7.7% 7 33.3% era properties of the served 13 32.5% 1 7.7% 7 33.3% era properties of the served 14 35.0% 2 15.4% 7 33.3% era properties of the served 15 37.5% 4 30.8% 9 42.9% CCR Sold Status (2009) 31 77.5% 9 69.2% 17 81.0% era properties of the served 15 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 32.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 37.5% 7 32.1% 0 0.0% era properties of the served 15 37.5% 7 37.	Private or other organization	3	7.5%	1	7.7%	2	9.5%	0	0.0%	0.29
15 37.5% 4 30.8% 1 44.8% 15.4% 11 4.8% 15.4% 11 5.2.4% 11 5.2.4% 11 5.2.4% 11 5.2.4% 11 5.2.4% 11 5.2.4% 11 5.2.8% 2 0.0% 4 30.8% 4 1 19.0% 13.3.5% 1 32.5% 1 7.7% 7 7.7% 7 33.3.% 13.3.% 10 25.0% 10 76.9% 10 76.9% 10 76.9% 10 76.9% 11 5.3.5% 1 15.4% 7 33.3.% 11 32.5% 7 53.8% 5 15.4% 7 33.3.% 11 32.5% 7 53.8% 5 15.4% 7 33.3.% 11 32.5% 7 53.8% 5 15.4% 7 33.3.% 11 32.5% 4 30.8% 9 69.2% 17 81.0% 11 37.5% 4 30.8% 9 69.2% 17 81.0% 11 37.5% 3 33.3% 11 37.5% 3 37.5% 13 30.8% 10 69.2% 17 81.0% 11 37.5%	Region									
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10 25.0% 3 23.1% 5 23.8% 4 19.0% 8 19.0% 4 19.0% 14 35.0% 6 46.2% 8 38.1% 13 32.5% 1 7.7% 7.7% 7 33.3% 13.3% 13 32.5% 1 7.7% 7.7% 7 2 33.3% 13 32.5% 1 7.5% 3 30.8% 10 76.9% 10 76.9% 10 76.9% 10 76.9% 10 76.9% 115.4% 7 33.3% 115.4% 7 30.8% 10 81.0% 115.6% 12 30.0% 2 15.4% 7 30.8% 10 75.5% 115.4% 7 30.8% 10 10.0% 115.6% 115.6% 115.4% 7 30.8% 10 10.0% 115.0% 1	South	15	37.5%	2	15.4%	111	52.4%	2	33.3%	2.49*
8 20.0% 4 30.8% 4 19.0% 14 35.0% 6 46.2% 8 38.1% 13 32.5% 1 77.% 7 33.3% 13 32.5% 6 46.2% 6 28.6% 10 25.0% 3 23.1% 6 28.6% 10 25.0% 10 76.9% 10 47.6% 13 32.5% 1 76.9% 10 76.9% 10 47.6% 13 32.5% 1 53.8% 5 23.8% 15 37.5% 4 30.8% 9 42.9% 18 (2009) 31 77.5% 9 69.2% 17 81.0% 18 100% edits NA 54.4% NA 62.2% NA 43.2%	Midwest	10	25.0%	3	23.1%	5	23.8%	2	33.3%	0.12
14 35.0% 6 46.2% 8 38.1% 13 32.5% 1 7.7% 7 33.3% 13 32.5% 6 46.2% 6 28.6% 10 25.0% 0 0.0% 5 23.8% 10 25.0% 10 76.9% 10 47.6% # % # % # % # % 12 35.0% 2 15.4% 7 33.8% 12 30.0% 2 15.4% 7 33.8% 13 32.5% 4 30.8% 9 42.9% 14 77.5% 9 69.2% 17 81.0% 15 37.5% 4 30.8% 9 42.9% 16 37.5% 17 5% 9 69.2% 17 81.0% 16 30.0% edits NA 54.4% NA 62.2% NA 43.2%	West	∞	20.0%	4	30.8%	4	19.0%	0	0.0%	1.21
14 35.0% 6 46.2% 8 38.1% 13 32.5% 1 7.7% 7 33.3% 13 32.5% 6 46.2% 6 28.6% 8 20.0% 0 0.0% 5 28.6% 10 25.0% 10 76.9% 10 47.6% # % # % # % # % # % 12 35.5% 7 53.8% 5 23.8% 12 30.0% 2 15.4% 7 33.3% 15 37.5% 4 30.8% 9 42.9% 16 17.5% 9 69.2% 17 81.0% 16 17.5% 9 69.2% 17 81.0% 16 17.5% 9 69.2% 17 81.0% 16 17.5% 9 69.2% 17 81.0% 16 17.5% 9 62.2% NA 43.2%	Size of area served									
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13 32.5% 6 46.2% 6 28.6% 8 20.0% 0 0.0% 5 23.8% 10 25.0% 10 76.9% 10 47.6% 12 55.0% 10 76.9% 10 47.6% 13 32.5% 7 53.8% 5 23.8% 15 30.0% 2 15.4% 7 33.3% 15 37.5% 4 30.8% 9 42.9% 16 7.5% 3 23.1% 0 0.0% 16 7.5% 3 23.1% 0 0.0% 16 7.5% 3 23.1% 0 0.0%	Medium	13	32.5%	1	7.7%	7	33.3%	5	83.3%	*/
8 20.0% 0 0.0% 5 23.8% 10 25.0% 10 25.0% 3 23.1% 6 28.6% 22 55.0% 10 76.9% 10 47.6% # % # % # % # % 47.6% 13.2% 7 53.8% 5 23.8% 12 30.0% 2 15.4% 7 33.3% 15 37.5% 4 30.8% 9 42.9% 11 77.5% 9 69.2% 17 81.0% 11 11 11 11 11 11 11 11 11 11 11 11 11	Large	13	32.5%	9	46.2%	9	28.6%	1	16.7%	0.94
8 20.0% 0 0.0% 5 23.8% 23.8% 25.0% 3 23.1% 6 28.6% 28.6% 2 25.0% 10 76.9% 10 47.6% 28.6% 2 25.0% 10 76.9% 10 47.6% 2 28.6% 13 32.5% 7 53.8% 5 23.8% 23.8% 12 30.0% 2 15.4% 7 33.3% 15 37.5% 4 30.8% 9 42.9% 10 10.0% 2 15.5% 3 23.1% 0 0.0% 10 10 10 10 10 10 10 10 10 10 10 10 10	Software									
10 25.0% 3 23.1% 6 28.6% 28.6% 10 25.0% 10 25.0% 10 25.0% 10 26.9% 10 47.6% 10 10.9% 10 47.6% 10 10.9%	In-house	∞	20.0%	0	0.0%	5	23.8%	3	50.0%	3.8*
22 55.0% 10 76.9% 10 47.6% # % # % # 96 13 32.5% 7 53.8% 5 23.8% 12 30.0% 2 15.4% 7 33.3% 15 37.5% 4 30.8% 9 42.9% 18 (2009) 31 77.5% 9 69.2% 17 81.0% 10g 100% edits NA 54.4% NA 62.2% NA 43.2%	CDC	10	25.0%	3	23.1%	9	28.6%	1	16.7%	0.18
# % # % # % 13 32.5% 7 53.8% 5 23.8% 12 30.0% 2 15.4% 7 33.3% 15 37.5% 4 30.8% 9 42.9% 18 77.5% 9 69.2% 17 81.0% 18 7.5% 3 23.1% 0 0.0% 19 7.5% 3 23.1% 0 0.0% 10 7 84.4% NA 62.2% NA 43.2%	Proprietary	22	55.0%	10	76.9%	10	47.6%	2	33.3%	2.13
13 32.5% 7 53.8% 5 23.8% 1 32.8% 1 30.0% 2 15.4% 7 33.3% 15 37.5% 4 30.8% 9 42.9% 15 12.0% 17.5% 9 69.2% 17 81.0% 108 (2009) 3 7.5% 3 23.1% 0 0.0% 108 100% edits NA 54.4% NA 62.2% NA 43.2% 13.8%	Consolidation effort	#	%	#	%	#	%	#	%	
12 30.0% 2 15.4% 7 33.3% 15 37.5% 4 30.8% 9 42.9% 1s (2009) 31 77.5% 9 69.2% 17 81.0% 1ng 100% edits NA 54.4% NA 62.2% NA 43.2%	Low	13	32.5%	7	53.8%	5	23.8%	1	16.7%	2.12
Ls (2009) 31 77.5% 9 69.2% 17 81.0% ling 100% edits NA 54.4% NA 62.2% NA 43.2% 34.2% S1.0% S1.	Medium	12	30.0%	2	15.4%	7	33.3%	3	50.0%	1.27
Lus (2009) 31 77.5% 9 69.2% 17 81.0% tus (2009) 3 7.5% 3 23.1% 0 0.0% ing 100% edits NA 54.4% NA 62.2% NA 43.2%	High	15	37.5%	4	30.8%	6	42.9%	2	33.3%	0.26
atus (2009) 31 77.5% 9 69.2% 17 81.0% status (2009) 3 7.5% 3 23.1% 0 0.0% sissing 100% edits NA 54.4% NA 62.2% NA 43.2%	NAACCR certification									
itatus (2009) 3 7.5% 3 23.1% 0 0.0% ussing 100% edits NA 54.4% NA 62.2% NA 43.2%	NAACCR Gold Status (2009)	31	77.5%	6	69.2%	17	81.0%	5	83.3%	0.36
ussing 100% edits NA 54.4% NA 62.2% NA 43.2%	NAACCR Silver Status (2009)	3	7.5%	3	23.1%	0	0.0%	0	0.0%	3.75*
NA 54.4% NA 62.2% NA 43.2%	Other characteristics									
	Percent of cases passing 100% edits	NA	54.4%	NA	62.2%	NA	43.2%	NA	76.7%	2.73*

	Low volume	Medium volume	High volume	F statistic
$N=40 \qquad \qquad N=13$		N = 21	N = 6	
Percent of records submitted electronically NA 82.3% NA	70.7%	NA 85.1%	NA 97.7%	2.95*

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Notes.

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 $I_{
m Low}$ volume: fewer than 10,000 cases; medium volume: 10,000-50,000 cases; high volume: more than 50,000 cases.

² Excludes Pacific Island Jurisdictions. Registry did not report cases diagnosed in 2006 and was still building capacity for case reporting.

³ Excludes NPCR registries that also receive SEER funding: California (San Francisco—Oakland, San Jose—Monterey, Los Angeles), Georgia (Atlanta), Kentucky, Louisiana, Michigan (Detroit), New Jersey, and Washington (Seattle-Puget Sound).

⁴ An asterisk (*) indicates that difference between low, medium and high volume registries are significant at the 10% level.

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Table 2

Average annual registry funding by volume of cases.

	$_{N=40}^{\mathrm{All}}$	Low volume $N=13$	Medium volume $N=21$	High volume N=6	F Statistic
NPCR funding					
Average	\$700,998	\$355,079	\$715,501	\$1,399,732	26.25*
95% CI	\$599,657-\$802,339	\$286,431-\$423,727	\$590,156-\$840,846	\$892,118-\$1,907,346	
Other federal funding					
Average	\$9,021	\$1,528	\$12,379	\$13,505	0.87
95% CI	\$3,372-\$14,670	\$0-\$3,731	\$0-\$26,940	\$0-\$29,335	
Non-federal funding					
Average	\$444,455	\$130,376	\$334,905	\$1,508,387	14.9*
95% CI	\$288,371-\$600,540	\$78,968-\$181,785	\$181,341-\$488,469	\$307,841-\$2,708,932	
Total annual funding, without in-kind contribution					
Average	\$1,137,469	\$482,198	\$1,051,410	\$2,858,425	24.04*
95% CI	\$899,539-\$1,375,399	\$401,667-\$562,729	\$866,104-\$1,236,716	\$1,233,855-\$4,482,996	
Total in-kind contribution					
Average	\$640,356	\$163,793	\$828,380	\$1,014,821	1.58
95% CI	\$256,463-\$1,024,248	\$87,028-\$240,557	\$253,091-\$1,403,670	\$0-\$2,899,209	
Total annual funding, including in-kind contribution					
Average	\$1,777,824	\$645,991	\$1,879,791	\$3,873,247	8.34*
95% CI	\$1,181,587-\$2,374,061	\$512,536-\$779,445	\$1,255,272-\$2,504,309	\$677,284-\$7,069,209	

Notes:

 $^{\it I}$ Average of three years of reported data: FY2009, FY2010, FY2011

Low volume: fewer than 10,000 cases; medium volume: 10,000-50,000 cases; high volume: more than 50,000 cases.

³Excludes Pacific Island Jurisdictions. Registry did not report cases diagnosed in 2006 and was still building capacity for case reporting.

4 Excludes NPCR registries that also receive SEER funding: California (San Francisco—Oakland, San Jose—Monterey, Los Angeles), Georgia (Atlanta), Kentucky, Louisiana, Michigan (Detroit), New Jersey, and Washington (Seattle-Puget Sound).

 $_{S}$ An asterisk (*) indicates that difference between low, medium and high volume registries are significant at the 10% level.

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Table 3

Cost Per Case for Core and Enhanced Activities by Volume of Cases.

	All <i>N</i> =40	Low volume N=13	$ \begin{array}{lll} \mbox{Medium volume} & \mbox{High volume} & F \mbox{Statistic} \\ N = & N = & \\ \end{array} $	High volume N=6	${\it F}$ Statistic
Cost estimates—no in-kind contributions					
Cost per case—all activities					
Average	\$60.77	\$100.88	\$44.86	\$29.52	12.7*
95% CI	\$47-\$75	\$68-\$134	\$36-\$54	\$17-\$42	
Cost per case—core activities					
Average	\$56.52	\$93.11	\$42.10	\$27.70	12.3*
95% CI	\$49~\$64	\$63-\$123	\$34-\$50	\$16-\$39	
Cost per case—enhanced activities					
Average	\$4.25	\$7.77	\$2.76	\$1.82	*0.8
95% CI	\$3-\$5	\$4-\$12	\$2-\$4	\$1-\$3	
Cost estimates—including in-kind contributions Cost per case—all activities					
Average	\$88.87	\$134.57	\$74.99	\$38.45	*0.9
95% CI	\$67-\$110	\$84-\$185	\$55-\$95	\$14-\$63	
Cost per case—core activities					
Average	\$82.77	\$124.82	\$70.09	\$36.03	*0.9
95% CI	\$63-\$103	\$77-\$173	\$51-\$89	\$13-\$59	
Cost per case—enhanced activities					
Average	\$6.11	\$9.75	\$4.90	\$2.42	5.1*
95% CI	\$4-\$8	\$5-\$14	\$3-\$7	\$0-\$4	

Low volume: fewer than 10,000 cases; medium volume: 10,000–50,000 cases; high volume: more than 50,000 cases.

² Excludes Pacific Island Jurisdictions. Registry did not report cases diagnosed in 2006 and was still building capacity for case reporting.

³ Excludes NPCR registries that also receive SEER funding: California (San Francisco—Oakland, San Jose—Monterey, Los Angeles), Georgia (Atlanta), Kentucky, Louisiana, Michigan (Detroit), New Jersey, and Washington (Seattle-Puget Sound).

⁴ An asterisk (*) indicates that difference between low, medium and high volume registries are significant at the 10% level.

 Table 4

 Difference in average cost per case for top 12 registry activities by volume of cases.

Activity	Average all registries	Difference—low vs high volume	Difference—medium vs high volume
Data collection/abstraction	\$8.33	\$10.01	\$6.19
Management	\$6.86	\$10.61	\$4.11
Administration	\$4.99	\$7.02	\$3.21
Analyzing and generating reports	\$3.40	\$3.82	\$2.43
QA: Visual editing	\$3.19	\$3.37	\$2.40
Case ascertainment	\$3.13	\$4.05	\$2.37
QA: Consolidating	\$3.12	\$2.82	\$2.29
Database management	\$3.08	\$4.36	\$2.14
Training of registry staff	\$2.84	\$3.75	\$2.07
QA: Tracking completeness and timeliness	\$2.77	\$3.90	\$1.61
Death certificate clearance	\$2.48	\$2.45	\$2.17
IT support	\$2.43	\$1.03	\$2.21

Notes:

 $^{{\}it 1}_{\rm Low\ volume:\ fewer\ than\ 10,000\ cases;\ medium\ volume:\ 10,000-50,000\ cases;\ high\ volume:\ more\ than\ 50,000\ cases.}$

 $^{^2} Excludes \ Pacific \ Island \ Jurisdictions. \ Registry \ did \ not \ report \ cases \ diagnosed \ in \ 2006 \ and \ was \ still \ building \ capacity \ for \ case \ reporting.$

³ Excludes NPCR registries that also receive SEER funding: California (San Francisco—Oakland, San Jose—Monterey, Los Angeles), Georgia (Atlanta), Kentucky, Louisiana, Michigan (Detroit), New Jersey, and Washington (Seattle-Puget Sound).